

**Rosalynn Carter's Testimony  
Senate Special Committee on Aging  
Hearing on Caregiving Issues  
September 10, 1998**

Mr. Chairman, Members of the Committee, I am very pleased to be here this morning and to have this opportunity to talk about caregiving. It is an issue about which I care deeply and one I have worked on in various ways for much of my life. From an early age, I helped care for my own ill and aging family members at home. And in more recent years I have witnessed again first-hand the needs and problems of caregiving as Jimmy's mother, brother and sisters have each struggled with terminal cancer.

I also speak today as one who remains heavily involved in caregiving. It has been an important part of my commitment to mental health issues, an interest I have pursued since my husband was governor of Georgia in the early 1970s. In addition, I serve as president of the Rosalynn Carter Institute (RCI) of our local state university, Georgia Southwestern, in Americus, Georgia. The institute was established to work on mental health issues. Since I have a good mental health program at the Carter Center in Atlanta, I didn't want to duplicate the work there, so we began working with those caring for people with mental illnesses. Our efforts quickly expanded to include all caregivers, whether caring for elderly, developmentally disabled, or those suffering from a physical or mental illness. The institute, now in its tenth year, is dedicated to improving the caregiving process by both professional and family caregivers. It has had a very positive impact in the communities surrounding the University, creating a model that could be replicated across the country. In addition, the institute has served as a convener for people who are interested in learning more about the opportunities and challenges associated with caregiving.

My concerns about caregiving also are integral to my work as honorary chair of the last acts coalition, a group of more than 180 organizations dedicated to improving care for the dying. Last acts involves health professionals, health officials and consumers in fostering three major changes: better communication among dying patients, their families and health professionals; more support for good end-of-life care in the medical community; and a cultural shift that would allow Americans to be more comfortable in facing death and dying.

I have shared much of what I have learned about caregiving in two books - *Helping Yourself Help Others* and *Helping Someone with Mental Illness*. Through all of my projects I've become more and more convinced that caregiving is not only a complex personal concern but also an important national concern.

I first encountered the issue when I was 12 years old, when my father became terminally ill with leukemia. My mother worked hard to care for him at home. As the oldest of four children, I helped out. Less than a year after my father died, my mother's mother also died, and my grandfather, who was 70 years old, moved in with us. He lived to be 95. I watched my mother work, care for 4 small children and care for my grandfather. I knew how hard caregiving was for her, but I did not know the extent of the problem until the RCI was established. (Today, the situation of my mother, who is 92 years old, is never far from my mind. I am her eldest daughter, and I make my home in plains, so she feels particularly reliant on me, although she receives care in an assisted living home, she wishes my work would require less travel.)

We were really charting new ground when the RCI began 987. We called many organizations and individuals involved with important health programs and found no one working on caregiving, although everyone assured us that it was an issue we should pursue. And after a needs assessment in our area - a survey done by students of the university - we realized that we were on the cutting edge of an issue that

greatly needed attention. We found the problems overwhelming emotionally, physically and financially. Caregivers in our own small community felt isolated, lonely, trapped by their situation, frustrated, not knowing where to turn for help or whether they were doing what was right and best for their loved one. Burnout was common. More than half of those we surveyed said they were suffering from burnout.

National statistics have shown that caregivers, when compared with the general population, are three times more likely to be depressed, two or three times more likely to take psychotropic drugs (such as tranquilizers), and 12% more likely to use alcohol as a way to cope with the stress. And yet almost all the caregivers we surveyed found something about the experience rewarding. One woman told us she had just wanted to run away - and did. She checked into a motel, leaving her father helpless in a wheel chair. She said that after a few hours, she felt so guilty that she went back home and of course, her father was just where she had left him. But even she felt a sense of pride in her task. At the end of the interview, she commented but nobody can take as good care of him[her father] as I can!

Others have said that caregiving deepens their compassion, strengthens their ability to listen, builds their confidence, and dispels their fears of the sick or disabled. For some, providing care has turned them into outspoken champions of the needs of the sick and disabled. Caregiving is an issue that is not going away. One of my colleagues has said there are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who will need caregivers. That's how universal this issue is.

Let's look at the scope of the problem more specifically. Twenty-five million Americans have identified themselves as family caregivers. One of the myths in our country is that the family does not care for its older members. In fact, studies show that the family is the number one caregiver of older persons, even when the one cared for is impaired. Only 5% of the population over 65 live in nursing homes; nearly half of these do not have a family and many who do are only in the nursing home during the final stages of disabling stroke, cancer or heart disease. The national alliance for caregiving reported in 1997 that 75% of caregivers are women. And while male caregivers typically handle legal, financial and housing matters, women usually provide personal care -bathing, feeding, washing, toileting and dressing. These are the kinds of demanding, continuous and relatively unrewarding tasks that put the caregiver at high risk of burnout.

The preponderance of women caregivers raises another concern - 25% of caregivers in one study were themselves between the ages of 65 and 74, with many of them responsible for the needs of elderly parents or spouses. These caregivers provide enormously valuable services, which have not been measured in financial terms and are not counted in the nation's gross domestic product. Many operate, as I have already pointed out, without adequate social and emotional support and respite. And nearly half of the family caregivers in 1997 said they were employed. That is above and beyond their caregiving roles. Many, however, have had to leave their jobs and thereby reduce overall productivity of the country. The number and age of elderly people providing and receiving care is a great concern now and will be even greater in the future as the baby boomers reach this age. The demographic trend in America shows that our population is aging quickly.

At the same time, modern medicine has an extraordinary ability to keep people alive. As a result, many now may live for months or even years with the severe illnesses that one day will cause their deaths. Another issue, Mr. Chairman, is that we know from our last acts initiative that most Americans die in hospitals, where they are all too often left alone, in unrelieved pain, and attached to life-sustaining machines they may never have wanted. One answer to this problem is a renewed focus on caring for patients at the end of life at home. This offers the advantages of familiar surroundings and permits patients to spend more time with the people who mean the most to them. Those cared for at home are more likely to receive palliative care - an approach that aims primarily to provide comfort, not cure, in

the face of a terminal illness. Here again, the signals point to a growing need to recognize and support caregiving for the significant role it plays in providing long-term care. What can be done to provide pro-family support for America's generous caregivers?

States and communities can play a vital role in preventing the downward spiral in which caregivers themselves become physically or mentally ill. The state of Pennsylvania has designed the family caregiver support program to help those who want to care for older relatives in their homes. The program assesses caregiver needs; counsels on ways to cope; trains family caregivers; provides information about other local, state, and federal support programs or resources, and offers one-time grants for home adaptations. Other states could replicate this or similar models. Much can be done in local communities. Educational, religious and other institutions can establish resource centers, and provide consultants or volunteers to help family caregivers care for their disabled loved ones. They can help establish support groups and more generally seek to increase awareness of informal caregiving and the value of their role in society. Efforts such as these can be very helpful, as demonstrated by the RCI. Mr. chairman, there are a number of policy-making areas I hope congress will explore so that government and business can help Americans give and receive better family care.

First, the family and medical leave act provides important benefits for elder care as well as child care. However, we need to have these benefits cover more employees in small business and to have the act amended to provide greater flexibility for caregivers during the course of their workday as well as with job retention and other supports. And because employers can be an important source of referral for their employees seeking social services, businesses could offer more information on how to find help for those with caregiving dilemmas.

Second, respite care could be added to medicare reimbursement. Respite care means having a substitute caregiver come into the home temporarily -perhaps for a day or even a few hours - so the primary caregiver can get relief. Appropriate respite care, giving necessary relief to the burdened caregiver, is economical in the long run since it reduces the exhaustion which may lead to nursing home admission or other expensive forms of care. Also, without such relief, caregivers themselves often become casualties. Third, government could foster demonstration projects that build effective support systems for caregivers. I am particularly proud of the success the Rosalynn Carter Institute has achieved in creating a support network for both family and professional caregivers. This network includes caregivers, representatives of local, state and federal government agencies (welfare, health, mental health, etc.), representatives of the religious community, and advocates who come together to talk about the problems involved and try to find ways to resolve them.

The network serves caregivers in a 16-county area of southwest Georgia, and its findings have been invaluable in planning programs. We are just now beginning to replicate this model on an experimental basis in another 16-county region in south Georgia. I have high hopes that the experiment will be successful in showing other communities the way to enhance their support of caregivers. On the national level, the Department of Health and Human Services may be able to use its regional structure to implement this idea or other similar projects nationwide.

Government may also play a role in creating programs that make a professional care manager available to informal caregivers. Again, the Rosalynn Carter institute has taken the lead in experimenting with this concept. We have received a Robert Wood Johnson Foundation grant to develop a certification program that prepares professionals to fill this role locally. Making a care manager available would be a significant way of alleviating caregivers' anxiety about having nowhere to turn for solutions. Finally, caregivers need better education and training to do their work well. Colleges and universities may be encouraged to offer courses for family caregivers. Such training would not only offer new skills, but also open channels of communication and cooperation among other caregivers in the community.

Grants could also be provided to schools of medicine, nursing (including nurse practitioners) and social work to find new ways that the health professions can better assist the informal caregiving network. This would help break down the barrier often created when health professionals deal strictly with the patient, omitting the insights that daily caregivers can provide - a very real problem for many caring for a loved one. We are trying to overcome this barrier, organizing 30 leading organizations of health care professionals and consumers into the national quality caregivers coalition of the Rosalynn Carter Institute. For several years, members of the coalition have come together in an effort to improve the skills these professionals and others bring to their work with family caregivers.

Mr. Chairman, I am very pleased that this committee is recognizing caregiving as an important national matter. Caregivers deserve our praise for the enormous contributions they make to the American family and to our country. But it is time to go beyond just recognition. Direct congressional action is needed to supplement the already remarkable role that the family, the individual and the voluntary sector make to our national life., business, too, must join in this common endeavor which affects every American family.

### **Recommendations for Congressional Action**

1. Amend the Family and Medical Leave Act to provide greater flexibility for caregivers during the course of their workday as well as with respect to job retention and other supports; extend the Act to small business and consider expanding unpaid leave to paid leave for significant caregiving (as is done in many other countries).
2. Add reimbursement for respite care to Medicare.
3. Develop demonstration projects that build effective support systems for caregivers.
4. Create a program that makes a professional "care" manager available to family caregivers.
5. Assist colleges and universities in offering courses for family caregivers; provide grants to schools of medicine, nursing (including nurse practitioners), and social work to find new ways that the health professions can better assist the informal caregiving network.
6. Provide Social Security credits, allowing caregivers to accrue caregiving hours to their earnings record in Social Security. This follows the lead of France and other countries. (In Germany, direct payments are given to the family, but this has proven controversial.)
7. Provide specific tax credits for caregiving activities, including a refundable tax credit for low-income caregivers.
8. Have the Congressional Budget Office develop a system to calculate the value of caregiving provided and measure its contribution to the nation's gross domestic product.
9. Develop demonstration projects throughout the ten regions of the Department of Health and Human Services to study cultural, ethnic and regional differences to ensure effective support systems for caregivers.
10. Provide additional funding to the National Institutes of Health to undertake a National Institutes of Health/National Institute of Aging initiative against frailty and dementia.

11. The Geriatric Medical Education funds from Medicare, the Veterans Administration and the National Institutes of Health should function together to further the development of geriatrics to ensure high quality, cost effective solutions - oriented care for older persons including prevention and rehabilitation.